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ABSTRACT

The increasing number of individuals infected with symptomatic human immunodeficiency virus (HIV) infection has created a need to examine public policy issues and to further efforts in planning, implementing, and evaluating services for individuals with HIV infection and their families. A working conference was convened, which identified several issues regarding HIV infection in special populations. Conference work groups formulated policy recommendations which are outlined and discussed in the report. These recommendations focus on the following policy areas: (1) service development should represent a partnership between professionals and the involved families; (2) no child or adult should be denied access to services due to infection with HIV; (3) the infected child or adult has a right to confidentiality concerning HIV status; (4) the individual who has both HIV infection and developmental disability will require an extensive range of services, including special assistance, training, and support for families and caregivers; (5) an extensive effort is needed to prepare program staff so that all such staff understand the nature of HIV infection, its limited infectivity, and specific service measures; and (6) funding mechanisms must be established or modified to reimburse additional costs resulting from services for individuals with HIV infection and developmental disabilities. (JDD)

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PUBLIC POLICY AFFIRMATIONS

affecting the planning and implementation of

DEVELOPMENTAL SERVICES

FOR CHILDREN AND ADULTS WITH HIV INFECTION

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PROLOGUE

The expanding epidemic of HIV infection in the United States is having an increasing impact on the developmental disabilities field. The number of children infected with symptomatic HIV are growing rapidly. There are now more than 1400 pediatric cases reported. Almost all children with congenital HIV infection manifest evidence of central nervous system dysfunction and the vast majority show signs of developmental delay or loss, mental retardation, or cerebral palsy. Most of the infected children are offspring of intravenous drug users or their sexual partners. Some children and adults, especially those with hemophilia, were infected by blood products. Adults with developmental disabilities are at risk of acquiring HIV infection through the same mechanisms as other adults. As a result, the number of adults with both HIV infection and developmental disabilities is also gradually increasing.

These concerns have created a need to examine public policy issues and to further efforts in planning, implementing, and evaluating services for children and adults with HIV infection and their families. A working conference on Issues and Public Policy in Developmental Disabilities and HIV Infection was held in Bethesda, Maryland, on November 9th and 10th, 1988. The conference brought together representatives of a wide range of governmental agencies, consumer groups, advocates, service providers, staffs of the University Affiliated Programs, and public policy experts in the human services field.

The conference format included a number of state-of-the-art presentations on practice in the field. Work groups then addressed the major areas of concern, and formulated policy recommendations. The resulting efforts were refined and consolidated to produce a consensus that reflected the varied and sometimes divergent points of view. These are presented in the subsequent section of this report.

Certain key principles emerged as the predominant elements in any proposed strategy to develop the services required for those with HIV infection and developmental disabilities. These can be briefly summarized as follows:

1. Future service development should represent a partnership between professionals and the involved families or other caretakers.

2. No child or adult should be denied access to any generic or specialized service due to a possible or actual infection with HIV.

3. The infected child or adult has a right to confidentiality concerning his or her HIV status.

4. The individual who has both HIV infection and developmental disability will require an extensive range of services, similar to others with developmental disabilities. However, special assistance, training, and support may be needed for the families and those caring for the person with infection.

5. There needs to be an extensive effort to prepare professionals and other staff in both generic agencies and those with special programs serving individuals with developmental disabilities so that all such staff understand the nature of HIV infection, its limited infectivity, and specific measures required to serve the individuals with infection and their families.

6. Funding mechanisms must be established or modified to reimburse for any additional costs that result from providing services for individuals with HIV infection and developmental disabilities.

1 CONFIDENTIALITY AND TESTING

1.1 The confidentiality of an individual's HIV status shall be respected.

HIV testing results are felt to be the property of a person inasmuch as they are an extension of a person's physical being. Violations of confidentiality are considered a violation of human and constitutional rights.

1.2 Test results shall be disclosed only to the client/patient, surrogate decision-maker, and medical care provider.

In varying circumstances, surrogate decision-makers may be parents, adoptive parents, foster parents as guardians, and child welfare agency managers. They should be involved in consideration of extending the testing information to selected persons with a carefully determined "right to know," such as day or residential program directors, school principals, respite care workers, and additional family members.

1.3 Antibody testing shall be voluntary, and performed only with informed consent.

The client/patient or their surrogate is the locus of authority for testing. Information shall be provided about the risks and benefits of testing.

1.4 Testing shall be performed only when medically indicated.

A medical recommendation for testing shall be based on current scientific knowledge and best medical practice.

1.5 Testing shall be accompanied by counseling and other supportive services.

Testing without the availability of counseling and supportive services for clients who may test positive is felt to be an unwarranted hazard. These supports shall include appropriate developmental services.

2 DISCRIMINATION, AND EDUCATION OF THE PUBLIC

2.1 Persons with developmental disabilities and HIV infection shall have the right to self-determination and full integration into society.

To achieve this there must be appropriate implementation of existing laws, rules, and regulations. Where intrusive laws exist, there shall be efforts towards law reform. Best practices should be identified, disseminated, adapted, and replicated. Community responsibility and acceptance shall be promoted by education and demonstration.

2.2 There shall be no discrimination within the general community based on status (or perceived status) regarding HIV infection, and especially there shall be none within the common effort for provision of developmental services.

This will be assisted by passage of the American Disabilities Act, including provisions protecting persons who have HIV infection. Other legislation may be needed for further areas of protection not covered in the ADA. The developmental disabilities service and consumer world should actively participate in the passage and implementation of anti-discrimination legislation at the state and local level.

2.3 Protection & Advocacy services are urgently needed to confront issues involving discrimination for persons with developmental disabilities and HIV infection.

Effective enforcement of the rights of persons with developmental disabilities and HIV infection can be achieved by providing legal advocacy services. A model for accomplishing this exists in the federally created Protection & Advocacy Systems for persons with Developmental Disabilities (PADD) and Mental Illness (PAMI).

2.4 Persons with developmental disabilities shall have access to effective and appropriate education and related services which will reduce the risk of their becoming infected with HIV.

Education for prevention of HIV infection in persons with developmental disabilities should begin with those who have most to do with access--such as policy makers, parents and guardians, service staff, and health educators. Appropriate curricula must be developed, adapted, disseminated, and evaluated. There are related issues in elements of AIDS education for the general public. Further, the AIDS service community should be informed regarding issues and concerns for persons with developmental disabilities.

3 AVAILABILITY OF SERVICES, INCLUDING FAMILY SUPPORT

3.1 Developmental services that are available for other children and adults shall be available as well for persons with HIV infection and their families.

When services are not available, they shall be established.

3.2 Developmental services shall be incorporated within planning and case management, acknowledging the special needs of clients who have both HIV infection and developmental disability.

A comprehensive design for case management shall be sought which attends to the multifactorial requirements usual in the situation of HIV infection. These may also include medical care, counseling, drug treatment programs, housing and transportation difficulties, financial concerns, family empowerment, and permanency planning.

3.3 The developmental service components shall be family-centered, community-based, and coordinated.

Families shall be defined in a way that reflects diversity of patterns and structures, including foster care. Services for children with HIV infection shall be related to individual child's needs and family preferences.

3.4 Developmental services, such as early intervention, therapies, preschools, and schools, shall be provided in an integrated setting.

Program planning shall involve short and long-term goals, which include an implicit sense of urgency for moving toward the achievement of fully integrated community services, in keeping with the principles of least restrictive alternative. In some circumstances, such as program effectiveness or the preference of families who have children with HIV infection, it may be temporarily necessary to provide community services in specialized settings.

3.5 The special developmental needs of most children with congenital HIV infection require that a developmental model be utilized in the design of support services.

Coordination with medical care is essential, and hopefully a single contact person can assure achievement of health care assistance for both the child and other family members who may have HIV infection. Pediatric HIV infection shall be considered a condition which places a child "at risk" of developmental delay for the purposes of eligibility for services provided under P.L. 99-457

3.6 There shall be increased efforts in training of personnel for developmental centers and community-based services, as part of a broader consciousness-raising program for the public about HIV infection.

Innovative approaches are needed to train professionals at all levels, including community health workers, to assist in service coordination and provision. New or improved funding mechanisms may be necessary to sustain these professionals. It is further acknowledged that resources must be allocated to program staff which recognize the intensity of services required and the support necessary to prevent burnout.

3.7 There shall be greater support given to the foster care system and to extended family members who assume responsibility for the care of children with HIV infection.

3.8 There shall be financing structures in place for the particular costs involved for individuals with HIV infection.

See Section 5.

4 PROGRAM LIABILITY

4.1 Programs providing services for persons with HIV infection and developmental disabilities shall not let liability concerns interfere with the delivery of services to their clients.

Lack of knowledge and uncertainty can provide a barrier to this resolve. Agencies shall develop specific policies and procedures to reduce the risk of liability.

4.2 No providers, whether private or public, shall discriminate against a person who is HIV infected.

Antidiscrimination provisions shall be strengthened in state statute to extend jurisdiction to private service providers. Liability concerns will be reduced when all providers are on an equal footing.

4.3 Service providers shall maintain accepted standards of least restrictive alternative, normalization, autonomy of choice, privacy, and integration.

Policies for clients with HIV infection shall be established which relate directly to the organization, are specific for the clients served, and are consistent with accepted professional practice regarding behavior, mental status, etc. These shall be reviewed periodically and maintained in a fashion consistent with current scientific knowledge.

4.4 Individual states, and the federal government, shall monitor provision of insurance to providers, in order to identify and analyze liability risks, minimize and manage risks, and limit individual losses.

4.5 Education shall be furnished to all providers, consumers, and insurers regarding the minimal danger which exists for transmission of HIV infection in the setting of developmental services.

This will reduce the fear of liability. Also, developing policy guidelines and standards of care will educate staff and reduce the anxiety associated with HIV infection.

5 INSURANCE

5.1 Symptomatic pediatric HIV infection shall meet the medical criteria for SSI eligibility.

5.2 There shall be revision of the Medicaid benefits system.

Incentives are needed to get children out of hospital care, and into community-based systems. Options shall be available which go beyond the requirement for institutional setting.

5.3 There shall be interrelations (integration) between systems of in-patient care and community social services, including foster care.

5.4 Key developmental services shall be covered by Medicaid payment.

Case management costs require support, and, as determined by the management team, assistance is also needed for nutrition, physical therapy, occupational therapy, speech therapy, mental health services, and related interventions.

5.5 Pediatric HIV infection shall not be excludable from existing private health insurance coverage.

5.6 Enrollment in group insurance coverage shall not be denied because of presence in the family of children with HIV infection.

5.7 For children not covered by Medicaid or private policies, there shall be catastrophic illness coverage, supported by state or local government at an affordable level.

5.8 Hospice services shall be reimbursible by public or private coverage.

6 EMPLOYEE RIGHTS AND RESPONSIBILITIES

6.1 The employee shall have the right to be educated about HIV infection and developmental disabilities; the employer shall have the responsibility to provide information, training, supervision, and support.

This applies to all workers, paid and unpaid. The training shall be generic for all employees (including the areas of general knowledge, attitudes, and values), and individual for specific job responsibilities (including information on death and dying). Curriculum development and delivery shall be provided by qualified trainers, including medical, developmental, educational, and social experts, and have input from employee and consumer involvement. Inservice training shall be ongoing, to address new staff, changes in treatment or knowledge, and management of difficult or emergency situations. Supervision shall be based on delineated policies and procedures which are consistently administered and uniformly enforced.

6.2 No employee shall be exempted from his or her responsibility to serve those infected with HIV.

6.3 Employees need to know they are serving individuals infected with HIV only where this is truly necessary to care for and protect the infected individuals appropriately.

Sharing of information about client and family HIV status will be guided by consistency with federal and state laws, and the preservation of confidentiality according to professional standards. See Section 1. In general, it can be stated that the current recommendations for improved hygienic practices in the circumstances of child care will adequately protect all parties against the risk of viral transmission.

6.4 The employer shall have the responsibility to provide and maintain a safe work environment, including furnishing adequate staffing patterns and facilities.

6.5 Employees shall have the right to employment and confidentiality in a service organization regardless of their own HIV status.

This should be assured within the framework of Section 504 of the Rehabilitation Act of 1973, as amended.

EPILOGUE

The policy conference identified the serious issues regarding HIV infection in special populations, particularly persons with developmental disabilities. These policy statements emerged out of the recognition that developmental programs must be committed to providing services for infants, children, and adults with HIV infection; developmental services must be prepared to accommodate the special needs prompted by HIV diseases.

As scientific knowledge develops concerning HIV infection and as the numbers of individuals with developmental disabilities and HIV increase in developmental services, new issues will emerge that will warrant a re-examination of these statements. However, HIV policy must be based on sound, rational knowledge as derived from public health experts and scientific research. The affirmations resulting from this conference have applied this knowledge to developmental services.

When considering issues posed by HIV infection, the disability community will face assaults on fundamental disability law such as treatment in a least restrictive setting, P.L. 94-142, Section 504, and other major landmark legislation protecting civil rights and providing services for persons with disabilities. Our challenge remains to assure appropriate developmental services to all persons with developmental disability--including persons with HIV infection.

Fortunately, the disability community has had an extensive history of dealing with demands for innovative services, which at the same time protect the rights of the involved persons. Developmental service providers must now integrate this history with the establishment of resources which address the particular requirements of HIV diseases.

The term "affirmation" is used here to connote that these statements are the beliefs, hopes, and recommendations of the conferees, derived by majority decision. The word reflects the definition of affirm: "to declare positively or firmly, to maintain to be true." In some instances the statements conform with existing laws or regulations; in others they can be viewed as convictions or expectations. We hope that they will serve as a basis for extensive local and national discussion. The conference leadership is grateful to the faith, energy, and expertise embodied in the illustrious group of persons who participated. In listing their attendance (see next pages) it should be noted that they were speaking as individuals in this circumstance, and it should not be construed that they were representing official policy determination by their organizations. Special appreciation is expressed for the editorial assistance of Harriette Derryberry, Beverley Johnson, and Theodore Kastner. Further materials from the conference, including the Affirmations, will appear in the August 1989 issue of Mental Retardation, the AAMR journal.

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